2001 Mortality Report

Prepared for the Massachusetts Department of Mental Retardation
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Evaluation and Research at the
University of Massachusetts Medical School/Shriver

A Report on DMR Deaths
January 1 – December 31, 2001

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EXECUTIVE SUMMARY

DMR reports a total of 362 deaths in 2001 among persons who were listed in the DMR Consumer Registry System (CRS). The 2001 Mortality Report includes both reported deaths (n=329) and deaths discovered in a cross-match with the CRS (n=33), whereas the 2000 Mortality Report included only reported deaths (n=322). The 369 deaths represent an increase of 12.4% in deaths over the 322 deaths cited in the 2000 Mortality Report, which may be explained by the aging of the population, increase in the number of persons listed in the CRS (+ 2%) and the addition of deaths discovered in the data cross-match (+10%). The addition of deaths discovered in the data cross-match to the 2001 Mortality Report produces a more complete and accurate picture of mortality in the DMR population than the report of the preceding year.

The average age at death of 60.7 years in 2001 is up slightly from 60.2 years in 2000, and represents the third consecutive year in which the longevity of the DMR population appears to have increased. Increasing life expectancy among persons with mental retardation is consistent with national trends. The older average age at death may also be due to an increase in the number deaths of nursing home residents that were reported or discovered in 2001. The crude death rate of 15.0 per 1000 persons at least 18 years of age and eligible for DMR supports increased from the previous year when it was 13.6. The 10% increase in the crude death rate in 2001 is caused by augmenting reported deaths with deaths discovered in the data cross-match.

Other key findings:

- *Deaths by geographic region.* DMR deaths were analyzed by the geographic region in which the deceased resided prior to death. For the second year in a row the Northeast (Region 3) had the lowest death rate (11.8 per 1000) and the youngest average age of death (57.5 years). Western MA (Region 1) had the highest death rate (21.1 per 1000), and the oldest average age at death (63.4 years). These statistics are consistent with the previous year and reflect the age distribution of population living in the various DMR regions.

- *Deaths by residence type.* Deaths were also analyzed by type of residence of the DMR population. The lowest death rates were found among the persons living in their own home or that of a relative (5.6 per 1000) and in DMR-funded community residences (13.0 per 1000). This is probably due to the higher percentage of younger persons living in these types of residence. By the same token, higher mortality rates were found in the population residing in DMR facilities (30.7 per 1000) and in nursing homes (120.6 per 1000), where the typical resident is older and more medically fragile.

- *Leading causes of death.* The three leading causes of death were heart disease, pneumonia and cancer. Together they accounted for 60% of all deaths. For the

third year heart disease was the leading cause of death, followed by pneumonia.[1] Cancer moved from the fourth leading cause in 2000 to the third leading cause in 2001.

- *Death investigations.* Twenty-one investigations of deaths occurring in 2001 were conducted concerning allegations of abuse, neglect or omission, of which one was substantiated. This is consistent with prior years. Eight cases were deferred to the Department of Public Health for investigation of the clinical circumstances surrounding death. DPH investigations typically involve review of medical and hospital records. In one case DPH found the complaints valid. DMR reported that seven (7) autopsies were conducted.

- *Reliability of data.* Death certificates were obtained for a stratified randomized sample of persons who died in 2001 and compared to DMR data. Discrepancies in the data were found in social security numbers (approximately 10%) and in one case the date of death was off by one day. These errors are small and do not negatively impact the quality of the mortality data or analysis presented in this report.

- *Clinical Mortality Review.* The Mortality Review Committee received mortality review forms and conducted a clinical review in 158 of the166 deaths for which clinical mortality review was required.[2] Compliance with the DMR policy on completion of mortality review forms was 95%. In the process of tracking down the missing mortality review forms, DMR found that some nurses did not complete a mortality review form because they had no record of receiving the DMR Death Report (n=3) or because of their interpretation of DMR policies and protocols for clinical reviews (n=2). Subsequently, DMR has clarified the ambiguity in the regulations and implemented a system to follow-up on deaths requiring mortality review.

DMR has made significant progress in increasing awareness of the importance of death reporting throughout Massachusetts and in matching data in the CRS with other files to identify deaths that are not reported to DMR via the mandatory death reporting system. DMR has implemented quality initiatives to assure better enumeration of deaths and more complete clinical information about the deceased than in the prior year. Future efforts should focus on reinforcing the DMR policy of timely completion of mortality review forms. This will require a systematic tracking system and mechanisms to provide support to the regional/area nurses as necessary. Mortality review is the best way to establish and confirm the cause of death and to identify situations and actions/inactions that put the DMR population at risk for adverse outcomes and mortality.

The 2001 Mortality Report demonstrates the advantages of a standardized reporting system based on death rates per 1000 that allows for comparisons between years and for

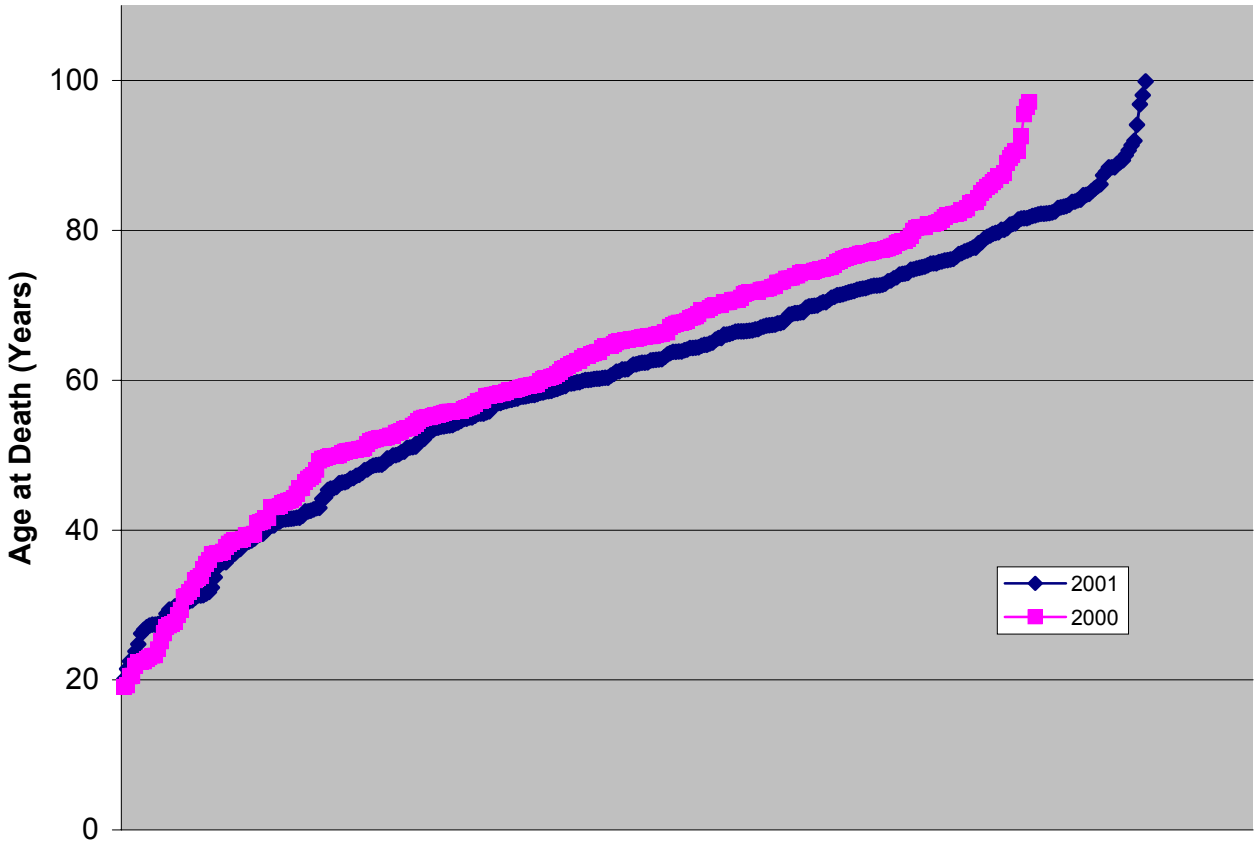
[1] Observing the current Vital Statistics format, pneumonia was divided into two categories: aspiration pneumonia and acute infectious pneumonia. See Leading Causes of Death, p.18 for further details.

[2] For criteria for Clinical Mortality Review see p.7.

trend analysis. There is consistency between the data in the 2000 and 2001 Mortality Reports.[3] The direction and magnitude of the statistics are what would be expected, and none of the differences between 2000 and 2001 findings were statistically significant except the small decrease in deaths of 18-24 year olds, which was significant ($p = 0.06$).

Exhibit 1 shows the age distribution at death for the DMR population in 2000 and 2001. The overlap in the two years demonstrates the similarity in the distribution of ages at the time of death during the two years. The cluster of deaths represented at the upper right end of the 2001 data demonstrates that the increase in the number of deaths is primarily among older individuals, which would be expected.

Exhibit 1
Distribution of Age at Death for DMR clients in Years 2000 and 2001



[3] While the 2000 and 2001 Mortality Reports are similar, they are not entirely comparable because of additional measures taken in 2001 to identify all deaths of DMR consumers, whether or not they had been reported via the DMR Death Report.

BACKGROUND

The Massachusetts Department of Mental Retardation (DMR) has maintained a standard process for reviewing, investigating and reporting the death of all individuals receiving DMR supports. For the third consecutive year, DMR contracted with the University of Massachusetts Medical School (UMass) to analyze its mortality data and to produce its annual mortality report. In 1999, UMass made a number of recommendations for improving the DMR reporting system that led to incremental improvements in the reporting of deaths in 2000 and 2001. By matching information in the DMR mortality database with information in the CRS, additional deaths were identified in 2001 that had not been reported to DMR. In 2000 DMR did not match files to identify deaths that were not reported to the Department directly.

Criteria for Clinical Mortality Review

In 1998 DMR set up a Mortality Review Committee, charged with strengthening the existing death reporting and review system and overseeing a process for providing clinical review of the death of any individual 18 years of age or older:

- Who was receiving at least 15 hours of residential supports funded or arranged by DMR, or
- Who was receiving residential supports certified by DMR, or
- Whose death occurred in a day habilitation program, or
- Who died while in transportation funded or arranged by DMR.

System Improvements

The 2000 Mortality Report contained analyses and calculations of death rates by age group, by geographic region and by type of residence that are consistent with standards used by the Massachusetts Department of Public Health Vital Statistics and the National Center for Health Statistics. The format used in the 2000 Report is used in the 2001 Mortality Report and allows for general comparisons of the DMR statistics for 2001 with those of the prior year. The two years are not directly comparable, however, because the 2000 report was based only on reported deaths and the 2001 report on reported and deaths discovered by cross-matching data with the CRS.

INTRODUCTION

Each year DMR conducts a study of the deaths of persons listed in the DMR consumer registry system and whose death was reported to DMR via the mandatory death reporting system. For the past three years (1999-2001), DMR has engaged the Shriver Center at University of Massachusetts Medical School to analyze the data provided by DMR, to conduct an independent review, and to prepare a report on mortality in the DMR population. DMR received a death report for 329 persons listed in the DMR CRS who died in calendar 2001, who were at least 18 years of age and eligible for DMR services at the time of their death. This represents a 2% increase in deaths reported to DMR over the

322 deaths cited in the 2000 Mortality Report. During the same period, the number of persons listed in the CRS increased by 2% from 23,599 to 24,103.

Verification of DMR Deaths

For the 2001 Mortality Report, DMR decided to take the additional quality measure of checking the number of reported deaths with the deaths that were noted in the DMR CRS system. In so doing, DMR uncovered an additional 54 deaths that occurred in 2001 of persons listed in the CRS. Research to clarify who these people were and why the deaths were not reported to DMR revealed that 21 were not active DMR consumers. They were individuals who had at one time or other initiated the intake process, but had never been found eligible for or received services from DMR, had not received DMR supports for many years, or had refused services. The remaining 33 persons were considered to be both DMR eligible and active. Their deaths should have been reported at the time of occurrence. The 362 deaths included in this report consist of both the reported deaths (n=329) and the deaths that were discovered through the cross-match with the CRS (n=33).

Nineteen of the deaths that were not reported to DMR in a timely manner occurred in nursing homes and health facilities where awareness of and compliance with the DMR policy is not universal. Other deaths involved persons living in their own home with a relative/guardian, living in non-DMR settings or living independently. However, five deaths were discovered that should have been reported within 24 hours on the DMR Death Report, among them three persons living in DMR-funded community residences and 2 living in DMR facilities until shortly before their death. When DMR followed-up on the deaths that were not reported with provider agencies, the most frequent explanation given for failure to report is that the deceased was hospitalized and/or transferred to a nursing home days or weeks before dying. The provider agency erroneously interpreted this as a change of residence. In the future to avoid confusion about the residence status of DMR consumers, DMR will clarify the existing definitions of "residence" for purposes of death reporting with all providers.

The average age of death for DMR consumers in 2001 was 60.7 years, with no appreciable difference between the average age of death for males and females. This compares with a life expectancy at birth in Massachusetts of 75.9 years for males and 80.8 years for females. For the third consecutive year, the average age of DMR deaths increased from 58.4 years in 1999, to 60.2 years in 2000 and 60.7 years in 2001. The increase may be an artifact of the increased reporting (or discovery) of deaths of older residents in nursing homes.

METHODOLOGY

The 2001 Mortality report analyzes information on all deaths occurring in calendar 2001 of all persons with mental retardation, 18 years of age or older, who have been determined to be eligible for DMR supports. In addition the deaths of all DMR

consumers who met specific criteria were subject to clinical mortality review *(see criteria on page 7*).

Data Collection and Review

DMR supplied the source data for this report based on DMR Death Reports that according to DMR policy must be completed within 24 hours of an individual's death. The 2001 Mortality Report also includes statistics on all deaths of persons who died in calendar year 2001 whose Death Report was received by DMR by the end of September 2002. A total of 329 deaths were reported to have occurred between January 1, 2001 and December 31, 2001. When it matched information in its mortality database with information in the CRS, DMR discovered an additional 33 deaths of DMR-eligible individuals that should have been reported. Those reports were subsequently obtained and procedures put in place for more accurate reporting in the future. DMR provided the following information for all 362 deaths:

- Name of the individual
- Date of birth
- Date of death
- Social security number
- Cause of death, if known
- Residence type
- DMR region
- Whether death was referred for investigation
- Whether a Mortality Review form was received

The data used to calculate death rates per 1000 by age group, region and type of residence were supplied by the DMR CRS of December 31, 2000.[4] The CRS contains information on every person eligible for DMR supports, including those who may not be receiving DMR services currently. In addition DMR made Mortality Review forms and clinical notes available to UMass for verification of information about the individuals subject to clinical mortality review.

Data Reliability

To determine the reliability of the mortality data provided by DMR, a 10% stratified randomized sample of the 362 deaths was created to compare the DMR information about the deaths with the actual Death Certificates obtained from DPH Vital Statistics using the following approach:

- The 10% randomized sample (n=37) was stratified by residence type in relative proportion to the residence type of the entire DMR population.

[4] UMass relies on the accuracy of information about the number of persons eligible for DMR services, their ages, region and type of residential placement. Inaccuracies in the CRS, if any, will be reflected in the numbers used to compute death rates in the DMR population. The number of DMR consumers by region and type of residence used in the calculations of death rates in the 2001 Mortality Report were based on data reported to UMass by DMR as of December 31, 2001.

- A copy of the DMR Death Report and the official Death Certificate were obtained for each of these 37 individuals.
- The data on the Death Report and Death Certificate were compared to the data in the DMR database to check the consistency of reporting from all three sources.

For the most part information from the DMR records and Death Reports agreed with the information provided on the Death Certificate. The most frequent discrepancy in the data was lack of agreement in social security numbers (10%). One date of birth was off by a day. These errors are common when manual information is transferred to an electronic database. It is also possible that some individuals used more than one social security number during their lifetime. The three persons whose DMR social security number did not agree with the one listed at DPH Vital Statistics were more than 50 years old. The comparison with official death certificates was most useful for confirming the cause of death. In some cases the death certificate shed light on the cause of and circumstances leading to death. This is especially true for persons living in nursing homes and in other community residences where DMR is not the primary provider of services.

DATA PRESENTATION

The 2001 Mortality Report displays DMR Mortality statistics in a format that is similar to the conventions used by DPH Vital Statistics. In addition to crude mortality rates, this report presents age-specific mortality rates and mortality rates by DMR geographic region and by type of residence. It also contains average age of death by gender, region and type of residence. Finally, DMR death statistics are compared with state and national statistics. The 2001 Mortality Report also compares these statistics with those in the 2000 Mortality Report.

Death Rate Calculations

Crude mortality rates were calculated for the entire DMR population and compared to national and state mortality figures. Death rates were also calculated by age category, region and residence type. The specific methodology employed by UMass for calculating death rates per 1000 for each of the categories was as follows[5]:

$$\text{Crude Death Rate} = \frac{\text{Number of persons who died in calendar 2001} \times 1000}{\text{(\# Persons in CRS 12-31-01)}}$$

$$\text{Age-specific Death Rate} = \frac{\text{Number of deceased in age category} \times 1000}{\text{(\# Persons in CRS in age category)}}$$

The turnover in the DMR population in any age category, residence type or region during a year is relatively small. Mobility among regions is also minimal, especially in older

[5] The 2001 death rates were calculated by a different method than that used in the 2000 Mortality Report. In order to make valid comparisons in this report, the 2000 death rates were re-calculated by the method used in 2001.

age groups. Some persons from community residences who are in declining health may be discharged to nursing homes prior to death. Others may have converted their residence on a permanent basis from community residence to nursing home.

Causes of Death

DPH Vital Statistics and the Federal Centers for Disease Control (CDC) National Center for Health Statistics (NCHS) have adopted the World Health Organization's International Classification System for Diseases (ICD-10) for the causes of death and the categories to which the diseases and conditions are assigned for the Leading Causes of Death. In 2001 an effort was made to classify the deaths reported to DMR by the underlying cause of death used in vital statistics. The causes of death were found on the DMR Death Report, and in the case of persons subject to clinical mortality review, confirmed through mortality review. In a number of cases it was not possible to determine the cause of death from the information made available to DMR. In addition to the randomized sample of 37 death certificates, UMass obtained and reviewed an additional 53 death certificates to ascertain and classify the causes of death for this report. The DMR death report alone may list only the immediate cause of death using terminology such as respiratory arrest or cardio-pulmonary arrest. The official death certificate often gives additional information of conditions and underlying disease processes that led to death. A more complete picture of the cause of death emerges from mortality review in which a clinician has been able to obtain information about health status and diagnoses of the person prior to death. In some cases, but not all, autopsy sheds further light on the cause of death.[6] Rates of autopsy are low both in the DMR population as well as the general population. The rate of autopsy in the general population has been declining nationwide.[7] Even when autopsies have been performed, DMR may request, but may not have the authority, without taking legal action, to obtain the reports.

DMR DEATH RATES

Crude Death Rates and Life Expectancy

DMR reported a total of 362 deaths in 2001, based on a total population served of 24,103 individuals 18 years of age or older for a crude death rate of 15.0 persons per 1000 for the DMR population. The DMR crude death rate increased from 13.6 the previous year, but the increase is not statistically significant.

In 2001, the average age of DMR reported death was 60.7 years, up from 60.2 years in 2000. There was no difference in the average age of death for men and women. The difference between the average age of death in 2000 and 2001 is not statistically significant, but represents the third year in which the DMR average age increased. The

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[6] Rosenberg, HM. *Cause of Death as a Contemporary Problem*, Journal of History of Medicine & Allied Sciences, 54(2): 133-53.1999.

[7] *The Autopsy as an Outcome and Performance Measure*, Agency for Healthcare Research and Quality, Evidence Report/Technology Assessment No. 58. http://www.ahrq.gov/clinic/epcsums/autosum.htm

current life expectancy at birth for the entire U.S. population is 76.9 years and for the Massachusetts population, 78.5 years.

Life expectancy among persons with mental retardation has historically been lower than for the general population, but improvements in life expectancy have been dramatic for this population in the past 30 years. Life expectancy among the DMR population in Massachusetts is consistent with this national trend.

DMR Deaths and Death Rates by Age Group

Table 1 presents DMR death rates by age group compared with national statistics. The death rate increases significantly for those 65 years of age or older in both the DMR and the general U.S. population. Age-specific death rates for the DMR population are higher than for the general population across all age categories. None of the differences between 2000 and 2001 death rates are statistically significant except for a decline in the death rate of persons 18-24 years of age, which was significant ($p = 0.06$).[8]

Table 1
DMR Reported Deaths and Death Rates by Age Group

	# Deaths	% DMR deaths	Death Rate/1000		U.S. Death Rate/1000
Age Group	**2001**	**2001**	**2001**	2000	2000
18-24 years	6	1.7%	1.6	3.6	0.8*
25-44 years	66	18.2%	5.8	4.4	1.6
45-64 years	136	37.6%	19.8	17.3	6.5
65-74 years	73	20.2%	55.2	55.4	24.3
75-84 years	61	16.9%	97.1	96.6	56.9
85+ years	20	5.5%	168.1	149.5	153.2
TOTAL	**362**	100%	15.0	13.6	8.7*

* The U.S. crude death rate includes all ages of the U.S. population from birth, whereas the DMR crude death rate applies only to persons over the age of 18 years and eligible for DMR services. U.S. death rate is for age group 15-24 years, whereas DMR death rate is for persons 18-24 years.

In calendar 2001, 43% of deaths occurred to persons 65 years of age or older, as compared to 45% in 2000 and 39% in 1999. Deaths reported among persons 45-64 years of age increased from 35% in 2000 to 38% in 2001. Deaths among persons under 45 years of age remained at 20% of the total in both 2000 and 2001. Deaths in the oldest age categories, 75-84 years and 85+ years, were also the same at 22% in both years.

[8] Chi-squared test, which is a non-parametric test of statistical significance between dichotomous variables. The "p" value is the probability that the two samples are statistically equal.

DMR Deaths and Death Rates by Region

DMR divides the Commonwealth into five administrative regions: Western MA (Region 1), Central MA (Region 2), Northeast (Region 3), Southeast (Region 5) and Metro (Region 6). The regions vary considerably in the size of their populations from about 3000 in the semi-rural Western MA Region to 8000 in the densely populated urban-suburban Metro Region. The regions also vary somewhat in their age distribution. A chart displaying the age distribution of the five regions appears in Appendix A. These differences are reflected in the number of deaths, death rates per 1000, and the average age of death.

Table 2 presents the number of DMR consumers per region, the number of reported deaths, the death rates and the average age of death. Other than in the Metro Region, the average age of death increased between 2000 and 2001. Region specific death rates remained consistent with the previous year. Western MA had the highest death rate for both years, of 18.9 for 2000 and 21.1 for 2001, and the oldest average age of death of 63.4 years. For two consecutive years, Western MA and Central MA had the oldest average age of death of 63.4 and 63.1 years, respectively. Southeast MA had the second highest death rate in both years of 15.3 in 2000 and 17.6 in 2001, accompanied by an increase in the average age of death from 57.9 years to 59.8 years. For the second year in a row, the Northeast Region also had the lowest death rate of 11.8 and youngest average age of death of 56.2 years. This compares to a death rate of 10.8 and an average age of death of 56.0 years in 2000. In the Metro Region, the death rate increased from 12.1 to 12.9 between 2000 and 2001, while the average age of death increased from 60.2 to 60.7 years. The statistics between the two years are similar and none of the differences between 2000 and 2001 are statistically significant.

Table 2
DMR Reported Deaths and Death Rates by Region

	Population	# of Deaths	Death Rates Per 1000		Average Age At Death in Years	
DMR Region	**2001**	**2001**	**2001**	2000	**2001**	2000
Western MA	2994	62	**21.1**	18.9	**63.4**	62.5
Central MA	4127	64	**15.5**	14.0	**63.1**	62.0
Northeast	4505	53	**11.8**	10.8	**57.5**	56.0
Southeast	4611	81	**17.6**	15.3	**59.8**	57.9
Metro	7916	102	**12.9**	12.1	**58.7**	61.5
TOTAL	**24,103**	**362**	**15.0**	13.6	**60.7**	60.2

DMR Deaths and Death Rates by Residence Type

Individuals receiving DMR supports live primarily in one of the following five categories of residences:

- "DMR Community"— A DMR-funded residential program or state-operated group residence. (Residential codes 3153, 4156 and 4157)
- "DMR Facility"— A state-operated institution funded by DMR that provides services as an intermediate care facility. (Residential codes 3200 and 4000)
- "Nursing Home"— A long-term care facility providing nursing care. This category also includes rest homes. (Residential code 3000)
- "Other Community"— Residents live at home with family members or independently in the community. (Residential codes 0000 and 9999)
- "Non-DMR"—A small segment of the DMR population lives in residences and facilities not covered by the above definitions and not funded by DMR, such as special education schools, DMH and MCB group homes, DPH hospitals, adult foster care funded by the Division of Medical Assistance (DMA) or in temporary residences and respite homes (includes any residential codes not cited above).

Variation in death rates among persons residing in different types of residences may be explained primarily by the age distribution of the DMR population within the different residence types. Details of the age distribution by type of residence appear in Appendix B. Less than 4% of those living at home or independently are 65 years of age or older. Of those living in DMR community residences, only 8% are over the age of 65 years. By way of contrast, 23% of persons residing in DMR facilities and 58% of those residing in nursing homes are over the age of 65 years. Compared to the preceding year, the population over 65 years of age has increased 2% in DMR facilities and 9% in nursing homes, while the percentage of the total DMR population living in these types of residence has declined.

Table 3 shows the distribution of the DMR population and the death rates by residence type. For two years in a row, the highest death rates and oldest average age at death are found in nursing homes and DMR facilities. While the average age of death in both residence types are similar, the death rate in nursing homes is almost four (3.9) times higher than in DMR facilities. This may be due to a number of factors including the age distribution of persons residing in nursing homes and the medical condition or conditions of the residents in nursing homes that led to their admission.

Consistent with the previous year, the lowest death rates were reported among persons living in the community in their own home or that of a relative. The average age of death increased in all types of residential settings. The population living in their own homes within the community also had the youngest age at death of 46.3 years, which represents an increase from 45.6 years in the previous year. Because the types of non-DMR residences vary and provide housing for so few of the DMR-eligible population, no conclusions can be drawn from the difference in average age of death in 2000 and 2001.

Table 3
DMR Reported Deaths and Death Rates by Residence Type

	Population	**# Deaths**	**Death Rates/1000**		**Average Age at Death in Years**	
Type of Residence	**2001**	**2001**	**2001**	2000	**2001**	2000
DMR Community	10,003	130	**13.0**	11.0	**59.0**	58.2
DMR Facility	1171	36	**30.7**	38.7	**68.1**	67.1
Nursing Home	1028	124	**120.6**	103.0	**66.9**	66.0
Other Community	11,109	62	**5.6**	4.5	**46.3**	45.6
Non-DMR	792	10	**12.6**	7.8	**57.7**	47.0
TOTAL	**24,103**	**362**	**15.0**	13.6	**60.7**	60.2

CAUSES AND PREDICTORS OF MORTALITY

Every year the National Center for Health Statistics (NCHS) at the Centers for Disease Control (CDC) publishes the leading causes of death in the United States. The Massachusetts Department of Public Health Vital Statistics also publishes the leading causes of death in Massachusetts. In recent years there have been several changes in the manner of reporting the cause of death at the national and state level. For instance, if a person dies of aspiration pneumonia, but Alzheimer's is an underlying cause of death, the cause of death is now more likely to be reported as Alzheimer's disease. Death due to Alzheimer's disease is rising everywhere, both because of the aging of the population and the increase in reporting it as the cause of death. In the U.S. Alzheimer's is now the leading cause of death for persons 85 years of age and older. Among the DMR population it is the fifth leading cause of death. Many DMR consumers, especially those with Down syndrome develop Alzheimer's disease in middle age, considerably earlier than its onset in the general population. Death reporting also distinguishes between different types of pneumonia: pneumonia due to acute infection (Influenza and Pneumonia) and pneumonia due to aspiration of liquids and solids (Aspiration Pneumonia).

Causes of death for DMR consumers in 1999 and 2000 were based on information provided to DMR on the DMR Death Report and/or Mortality Review Form. In those years DMR did not follow the NCHS classification system, based on the World Health Organization (WHO) ICD codes to identify the underlying cause of death. Currently, NCHS uses a computer protocol to review conditions and contributing causes of death in order to select an underlying cause based on the information provided on the official Death Certificate. For example, if an individual undergoing chemotherapy becomes immune-suppressed and has a massive infection (septicemia), the cause of death would be listed as cancer, not sepsis. Some causes of death are more common in the DMR population, for instance reflux disease (GERD) and seizures are common among persons with mental retardation. DMR deaths due to hemorrhage of the gastro-intestinal system and cardio-pulmonary arrest with seizure therefore appear on the death certificate with much greater frequency. For this reason the reader will find some DMR deaths attributed to diagnoses that do not appear among the leading causes of death in the general population.

In 2001 a serious effort was made to classify the deaths reported to DMR by the underlying cause of death used by NCHS. The causes of death were found on the DMR Death Report, and in the case of persons subject to Mortality Review, confirmed through mortality review. A physician and/or nurse on the Mortality Review Committee reviewed the available information and assigned a cause of death using NCHS categories. To complete research on causes of death, UMass retrieved and reviewed 90 death certificates from Vital Statistics. In only 5 cases was there insufficient information available to assign a specific cause of death. In 2001 these were deaths were categorized as Unknown.

Heart disease was the leading cause of death for the DMR population, the general population in Massachusetts, and in the U.S. Aspiration pneumonia and cancer were the second and third leading causes of death in the DMR population, while the second and third leading causes of death for the Massachusetts and U.S. population were cancer and stroke. Among the DMR population, respiratory problems are common. Some originate early in life because of premature birth. Swallowing problems due to long-term use of anti-convulsants (seizure medication), coordination difficulties (cerebral palsy), lack of mobility, feeding problems and reflux disease are also more common in the DMR than in the general population. These conditions contribute to a high rate of aspiration pneumonia and chronic respiratory disease.

Of the 45 cancer deaths, information on the primary site was not available to DMR for 25 individuals. Information on the death certificate and/or mortality report indicates that a considerable number of cancers had metastasized. Among those that were reported by site (n=20), there were three brain tumors and lymphomas; two cancers each of the bladder, breast, colon and pancreas; and one of kidney, lung, skin (melanoma), ovary, prostate and stomach. While the frequency and types of cancers recorded in the DMR population appears to be different from that in the general population, it is not known if the types of cancer found in the DMR population would be more similar to that of the general population had the primary site been identified. Lung cancer (followed by colon cancer) is the leading cancer in the general population, and since smoking is less common in the DMR population, a lower frequency of lung cancer would be expected. It is not possible to draw any conclusions from the data available on the cancer deaths.

Sepsis, or overwhelming infection, occurs in populations that are immune suppressed (persons with HIV/AIDS or undergoing chemotherapy) and among the frail elderly and persons who have difficulty in accessing timely medical care. The inability of many persons with mental retardation to describe their own health changes and pain, before it becomes obvious to caregivers, is also a barrier to timely medical consultation and treatment. Careful noting of changes in behavior, bowel patterns or temperature might reduce, but not eliminate deaths due to sepsis.

Improvements in diagnosis and reporting accounts for the increase in persons for whom Alzheimer's was reported as the underlying cause of death, in both the general and the DMR population. A decade ago many of these deaths would have been categorized by the immediate cause of death, such as sepsis, aspiration pneumonia, acute infectious pneumonia, accidents (choking) or cardio-pulmonary arrest, rather than Alzheimer's.

The twelve accidental deaths included choking (6), trauma (4, mostly vehicular), poisoning (1) and burns (1). Other causes of death include renal or kidney failure (10), pulmonary embolism (8), gastro-intestinal hemorrhage (6), liver failure/cirrhosis (5), and degenerative diseases, both congenital and acquired (4).

Table 4 ranks the ten leading causes of death in the U.S. and Massachusetts and compares them with the leading causes of death reported to DMR.

Table 4
Leading Causes of Death

Rank	U.S. 2000	MA 2000	DMR 1999*	DMR 2000*	DMR 2001
1	Heart Disease	Heart Disease	Heart Disease	Heart Disease	Heart Disease
2	Cancer	Cancer	Pneumonia	Pneumonia	Aspiration Pneumonia
3	Stroke	Stroke	Chronic Respiratory Disease	Chronic Respiratory Disease	Cancer
4	Chronic Respiratory Disease	Chronic Respiratory Disease	Cancer	Cancer	Sepsis
5	Accidents	Influenza and Pneumonia	Sepsis	Sepsis	Alzheimer's
6	Diabetes	Alzheimer's	Gastro-Intestinal	Nephritis	Influenza and Pneumonia
7	Influenza and Pneumonia	Diabetes	Nephritis	C-P Arrest/ Seizure**	Chronic Respiratory Disease
8	Alzheimer's	Nephritis	Alzheimer's	Alzheimer's	C-P Arrest/ Seizure**
9	Nephritis	Septicemia	Seizure-related	Stroke	Accidents
10	Septicemia	Accidents	Accidents	Gastro-intestinal	Stroke

- Causes of death for DMR consumers in 1999 and 2000 were based on information provided to DMR on the DMR Death Report and/or Mortality Review Form. Causes of death in 2001 were assigned by clinicians based on the Death Report, Mortality Review and in 25% of cases confirmed by Death Certificates.

** Includes sudden deaths reported as cardio-pulmonary arrest whether or not seizure was present.

CLINICAL MORTALITY REVIEW

DMR conducts a clinical mortality review of the death of any individual 18 years of age or older who meets mortality review criteria.[9] Consistent with DMR policy, DMR area nurses are expected to complete a mortality review form for every person subject to mortality review within 30 days of death. In 2001, 166 persons were subject to Mortality Review for which DMR received 158 completed mortality review forms, producing a compliance rate of 95% with DMR policy. Mortality review forms were not submitted to DMR for 8 persons (5%) who were living in residences funded or operated by DMR. One explanation for the 5% non-compliance with the policy was some confusion about responsibility for completing the clinical mortality review form when a DMR or DPPC investigation was occurring. A few area offices assumed, incorrectly, that they were not to conduct mortality review if DMR or another state agency was conducting an investigation. DMR has subsequently clarified the policy to the regional/area offices.

In 2001 the Mortality Review Committee began work on modifying the mortality review form to better organize information pertinent to clinical mortality review. In certain circumstances, mortality review led to requests for follow-up by DPH, consultations with clinicians, identification of contributing and underlying causes of death, and recommendations for improvements in the DMR system of health care monitoring at the provider agency and/or statewide level.

In 2001 the Mortality Review Committee also recommended that the criteria for Mortality Review be extended to include all persons receiving the service model "individual supports" from the Department. DMR may want to re-visit this recommendation in light of the considerable difficulty in retrieving information on persons who reside in non-DMR residences (but receive 15 hours or more of DMR support), and in light of the constraints imposed by HIPAA. Families/guardians may be willing or unwilling to speak with a DMR nurse about the deceased. DPH can obtain medical records when it is conducting an investigation into the quality or appropriateness of clinical care in settings that they license. But currently, DPH is not authorized under law to share those records with another state agency. DMR will only be informed by DPH if a complaint about clinical care of a DMR consumer is investigated and found "valid."[10] When medical information is not accessible, the best information for DMR on the cause and circumstances of death is the Death Certificate.

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[9] For criteria for Mortality Review see Background section, p.7.

[10] Health care facilities are required to protect patient privacy, and unlike DPH, DMR does not have statutory authority to obtain medical records. Informally, physicians are able and generally willing to answer questions about health status and diagnoses with a DMR nurse, especially if they have spoken in the past.

INVESTIGATIONS

Whenever there is any indication that the death of an individual with mental retardation was the result of abuse, neglect or omission, the Disabled Persons Protection Commission (DPPC), the DMR Investigations Division, or the Department of Public Health (DPH) conducts an investigation into the causes, manner, and circumstances of death.

Also subject to investigation are any deaths that meet medico-legal requirements outlined by the Massachusetts General Law, chapters six and thirty-eight *("Any death in which the Chief Medical Examiner takes responsibility for determining the cause and manner of death, to include all cases of suspected homicide, suicide, accidental drug overdose, or sudden and unexpected natural deaths.")*

The Investigations Division keeps its records by the calendar year in which the investigations were conducted. Some of the investigations of 2001 deaths were still under investigation in 2002. For this report, the investigations are reported by the year in which the death occurred. There were a total of 21 investigations of deaths that occurred in 2001. This is comparable to the number of investigations in prior years. After preliminary review, five of those complaints were dismissed as having no reasonable cause to believe that the death was a result of abuse or mistreatment, were referred for administrative review or were resolved without investigation.

Depending upon the nature of the allegation or complaint, the case may by investigated by the Disabled Persons Protection Commission (DPPC), by DMR, or by the Department of Public Health (DPH). Some deaths may involve more than one investigation by more than one state agency, such as situations in which a complaint of neglect, abuse or omission is made to DPPC/DMR and about the quality of clinical care to DPH. Eight cases were referred to DPH in 2001, as compared to one in 2000. One DPH complaint was determined to be valid. DPH is charged with investigating allegations of abuse, mistreatment or neglect in certain licensed health facilities including hospitals, rehabilitation hospitals and nursing facilities. When an allegation or complaint is confirmed, DMR and DPPC use the terminology "substantiated." If allegations of abuse, neglect or mistreatment is substantiated DPH uses the term "valid."

In 2001 DMR reported seven autopsies, as compared to none in the prior year. Medical examiners are not required under law to notify DMR of requests for autopsy and, unlike DMH, DMR has no statutory authority to obtain autopsy reports. The Mortality Review Committee undertook a major review of its purpose and processes during 2000-2001, resulting in recommendations for more focus on the appropriateness and timeliness of clinical care and on obtaining autopsies to ascertain the cause of death. One autopsy substantially altered the cause of death from what was initially reported.

The Department of Public Health is not required under law to share its findings with DMR. But pursuant to an agreement between DPH and DMR reached in 2002, DPH now routinely provides copies to DMR of all complaint investigation reports involving individuals with mental retardation or developmental disabilities residing in nursing

facilities. Upon request, DPPC shares its reports with DMR. In one of two investigations conducted by the DPPC the allegation of abuse and/or neglect was substantiated. In one case further investigation was requested and the cause of death was established by autopsy. One case was referred to the District Attorney. It involved the sudden death of person less than 30 years of age for which the cause of death is still unknown and for whom no autopsy was performed prior to cremation.

Table 5 shows the number of investigations, the agencies involved and the disposition in 2001 and prior years according to DMR records.

Table 5
Investigations and Autopsies of DMR Deaths by Agency*

Investigating Agency	1997	1998	1999	2000	2001
DMR	15	12	7	5	5
DPPC	4	2	5	1	2
DPH	0	3	2	1	8
District Attorney/Law Enforcement	0	0	0	3	1
Other/dismissed	1	3	5	3	5
TOTAL	**20**	**20**	**19**	**13**	**21**
# Substantiated	2	3	0	0	1
Autopsy (Medical Examiner)	NA	NA	NA	0	7

*Data for this chart were provided by DMR without independent corroboration or review of reports by UMass.

SPECIAL STUDY: EARLY AGE OF DEATH

At the request of the Mortality Review Committee, UMass conducted a more extensive review of deaths that occurred to persons 35 years of age or less to ascertain whether the circumstances of death were substantially different from those of older persons who died in 2001. Of the 37 individuals who were identified, 36 were age 35 years or less at the time of death. One case was eliminated because the date of birth in DMR records was incorrect; the individual was actually 36 years of age. Of the persons included in the study, 19 (53%) were male and 17 (47%) were female. Twenty-one (58%) lived in the community in their own home, usually with parents or a relative; nine (25%) lived in DMR-funded community residences; and, six (17%) resided in nursing homes. The living arrangements are consistent with the types of residences of the entire DMR population in this age group, with the exception of the greater than expected number of persons in nursing homes. Young residents of nursing homes are most likely to have been placed in these facilities because of their medical needs. Two of the nursing home

residents appear to have been living there because of terminal conditions. Comparisons between 2000 and 2001 deaths of younger persons appear in **Table 6.**

Table 6
Deaths of Persons 35 Years of Age or Less

	Male		Female		TOTAL	
Residence	2000	**2001**	2000	**2001**	2000	**2001**
DMR Community	3	**3**	0	**6**	3	**9**
Facility	0	**0**	0	**0**	0	**0**
Nursing home	2	**3**	2	**3**	4	**6**
Own Home	8	**13**	2	**8**	10	**21**
Non-DMR	0	**0**	0	**0**	0	**0**
TOTAL	13	**19**	4	**17**	17	**36**

The seven of the nine deaths (78%) of persons between 18-35 years of age that occurred in DMR-funded community residences received mortality review, of which three were referred to DPH for investigation of issues related to clinical care. Autopsies were requested in seven cases, of which only two were known to DMR. Medical examiners perform an autopsy when the death is sudden or suspicious, especially if the individual is young and appears healthy. .

Four cancer deaths were expected. Three persons with muscular dystrophy had been in declining health and death was anticipated. Bowel perforation with sepsis was the cause of two deaths and aspiration pneumonia the cause of another. One person with Prader-Wiilli syndrome choked to death and another was a victim of a motor vehicle accident. One death was attributed to a shunt malfunction in an individual with hydrocephalus. The cause of death is unknown in two cases of persons living in their own home.

Within the MA DMR population, of the 36 cases of young death, five (14%) were Black, one (3%) was Hispanic and five (14%) were foreign-born. In Massachusetts and in the U.S. younger populations groups are more racially and ethnically diverse. While information on the racial and ethnic background of the entire DMR population is not available, in the stratified sample representative of the DMR population (n=37), only 5%, as opposed to 31%, were minorities or foreign-born. A national study on mortality of persons with Down Syndrome found earlier age of death among racial minorities [11]

CONCLUSIONS

The 2001 Mortality Report demonstrates the strength of a standardized death reporting system based on death rates per 1000 and trend analysis. There is consistency between

[11] Friedman MD, JM. Racial Disparities in Median Age of Death of Persons with Down Syndrome – US 1968-97, CDC National Center on Birth Defects and Developmental Disabilities, June 2001.

the statistical data in the 2000 and 2001 Mortality Reports. The direction and magnitude of the statistics are what would be expected, and none of the differences between 2000 and 2001 data were statistically significant with the exception of a moderate reduction in the proportion of deaths occurring to persons 18-24 years of age ($p = 0.06$). The number of persons in this age group is relatively small and may be atypical because many persons do not enter the DMR service system until after 22 years of age when the public education entitlements cease.

Because of the deaths identified in addition to those reported to DMR, the death rates per 1000 in the 2001 Mortality Report are higher than in 2000. The overall death rate of 15.0 in 2001 was 10% above the death rate of 13.6 in the 2000 Mortality Report. The 10% increase in crude death rate corresponds to the 10% increase in number of deaths included in this report by adding discovered deaths to reported deaths. The number of deaths is the numerator in the death rate calculations. The DMR CRS numbers are used in the denominator of the calculation. In both the 2000 and the 2001 Mortality Report the CRS statistics used for the calculation of age-gender, type of residence and DMR regional death rates were comparable. Assuring the accuracy of all the information in the CRS should be a priority for future reports. Any reduction in the CRS would be expected to increase the death rates because more deaths are occurring within a smaller population group.

Exhibit 1 shows the age distribution at death for DMR in 2000 and 2001; the overlap of the age distribution in the two years demonstrates the similarity between the two years and the increasing number of deaths in the oldest age groups (*see Executive Summary).* The 2000 Mortality Report is based only on deaths reported to DMR. The 2001 Mortality Report is amplified by deaths of persons in the DMR CRS whose deaths were not reported, but discovered in connection with data quality improvement initiatives within the Department. DMR can be reasonably sure that the reports of both years are a fairly accurate representation of mortality in the DMR population, and that the overall statistics are an appropriate baseline against which to measure mortality trends in the future.